Therapeutic goals of hospice care environment: A systematic literature review

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ABSTRACT: Identification of environmental Therapeutic Goals (TGs) has proven essential in providing useful guidance for planning and design (Cohen & Weisman 1991). Though age-specific environmental dimensions have been suggested by several researchers during 1980's to 1990's, none of them focused on dying patients and their experience in hospice care environment, so the need for categorizing dimensions for hospice environment is evident. The objective of this study is to identify the Therapeutic Goals of hospice environment focusing on patients' experience. This study employed a systematic literature review with an approach developed by Hawker and colleagues in 2002. This study had considered a wide-ranging literature search: 7 electronic databases search (PubMed, PsycINFO, Social Science Citation Index, Science Citation Index, ProQuest Dissertations & Thesis, Avery, and Cochrane Library), reference list search, examination of literatures recommended by relevant experts, and Google search for books, reports, and guidelines. In total 48 literatures included; 39 full text articles, 2 books, 5 guidelines, and 2 reports. The data has extracted from these literatures onto a standard template (matrix) for comparison and analysis for coding and thematic development. The study identified eight themes as TGs which have direct influence on patients' experience of hospice care environment: provide continuity of self, provision of access to nature, provision of privacy, facilitate social interaction, maximize safety & security, provision of autonomy, regulate stimulation, and provision of spiritual care. These goals reflect two characteristics; each expresses a basic or derived major patient's need, and a potential environmental facilitator for the satisfaction of the need (Lawton et al. 2000). As the physical environment of hospice has significant impact on the patients' quality of life and the possibility of a good death (Cohen et al. 2001), these TGs have a positive effect on patients' lives.

KEYWORDS: Hospice, Palliative care, End-of-life, Dying, Therapeutic environment.

INTRODUCTION

The physical environment of hospice has significant impacts on the patients' quality of life and the possibility of a good death (Cohen et al. 2001). The physical environment is a part of the entire care milieu which also includes personal, social and organizational dimensions (Figure–1) (Cohen & Weisman 1991). The organizational component is conceptualized in terms of the policies and programs, the social component is represented by family and fellow residents, and the architectural component is defined in terms of the experiential qualities or attributes of environments (Cohen & Weisman 1991). The TGs serve as unifying intentions which can direct congruent decision-making in the organizational, social, and physical realms and thereby provides a useful foundation for planning and design (Cohen & Weisman 1991). For instance, according to Lawton et al. (2000), eight core dimensions of TGs for the environment for aging person with dementia include safety, orientation, functionality, stimulation, personal control, social interaction, continuity and change. These authors go on to suggest that these dimensions reflect two characteristics. First, each dimension expresses a basic or derived major human need. Second, the dimension is one in which a potential environmental facilitator for the satisfaction of the need is evident. The physical settings of hospice along with the carefully designed organizational environment can contribute to the realization of desired therapeutic goals and have a positive effect on the lives of dying patients.

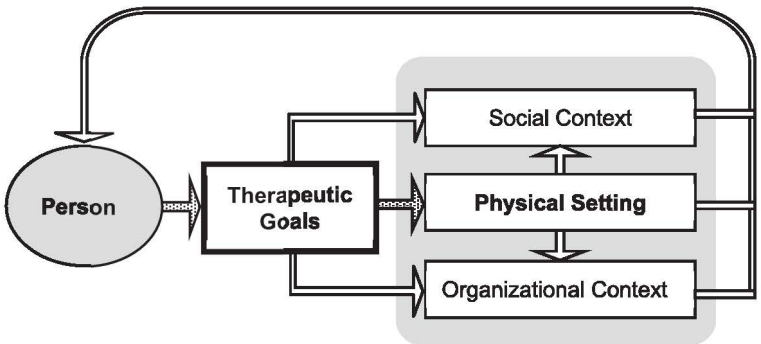

Figure 1: A conceptual framework for the organization of the person-environment system (Adapted from Figure 1.2, Cohen & Weisman 1991).

Since the beginning of hospice movement in America, mid-1970s, the architectural design of hospice has been considered similar to nursing home (Verderber & Refuerzo 2006). During 1980's to 1990's, several researchers have suggested age-specific environmental dimensions for nursing home settings, but none of them focused on environment for dying patients (Lawton 1983; Lawton et al. 1992). But in recent years, several studies begin to suggest differences in therapeutic needs of the hospice environment. Hospice patients are mostly bed-bound, their physical, social and spiritual demands are different, and family accommodations plays a significant role in care (Nakashima 2002; Silver 2004; Evans et al. 2006; Anderson 2007; Rowlands & Noble 2008; Rijbi et al. 2009; and Brereton et al. 2011). Also, several literatures (books, reports and manuals) have published addressing the design issues of hospice and palliative care facilities (Verderber & Refuerzo 2006; Moorhouse 2006; Worpole 2009). What is missing from the hospice literature is the identification of therapeutic goals by which to inform integrated design decision-making. The need for categorizing such therapeutic goals for the hospice and palliative care environment is evident and this is the aim of this study. The question guiding this study is "What does the literature suggest are the appropriate dimensions of the 'environment as experienced' and therapeutic goals for the hospice environment?"

1.0 METHODS

To develop a research-supported list of TGs for the hospice environment, a narrative literature review was completed using a systematic approach focusing on patients' experience of hospice care. This study employed the literature review approach developed by Hawker and colleagues (2002) which outlines a process by which to systematically and objectively reviewing research from different paradigms. A search of 7 electronic databases from 1998 to 2012 were searched including PubMed, PsycINFO, Social Science Citation Index, Science Citation Index, ProQuest Dissertations & Thesis, Avery and Cochrane Library. A total of 847 papers were identified and assessed by their title and abstract using the inclusion and exclusion criteria: published since 1998, written in English, for adult patients, hospice or palliative care facility. After the screening of titles and abstracts, 127 articles were selected. The second stage was assessing each of these papers objectively to seek relevancy. Any form of information about the physical environment of hospice or palliative care found in the text was included: 27 literatures were found eligible. An additional 12 records were identified from reference tracking. From Google search and experts' suggestions 2 books, 5 guidelines and 2 reports were added. Total 48 literatures included. The details of literature search and selection process are shown in Figure-2, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Moher et al. 2009).

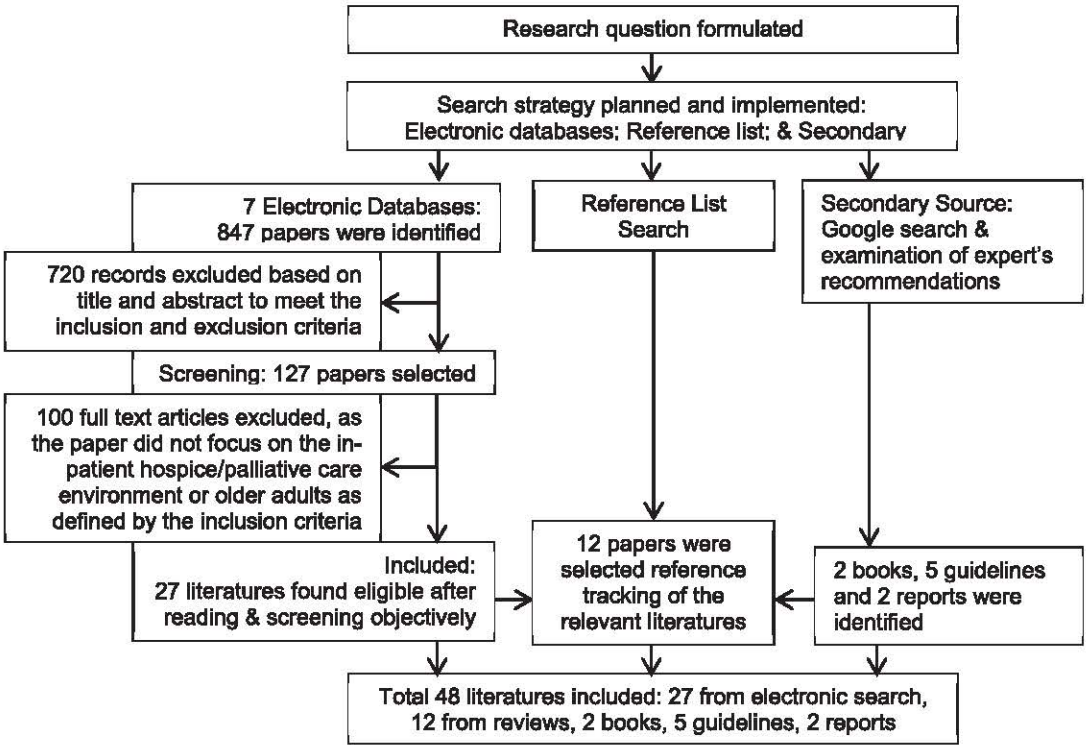

Figure 2: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart

2.0 REVIEWS

All of these literatures have examined the physical environment of hospice or palliative care service. Some focused on design issues and some studied physical environment in the context of wider issues such as quality of care, patients' perception and experience, staffs' or family members' perspective about hospice care or setting, and patients' views on a particular concept such as dignity or a 'good death'.

Two books, five guidelines, two reports, two dissertations, and ten journal articles focuses on designing aspects of hospice and palliative care environment. In 2006, Verderber & Refuerzo wrote a major reference book "Innovations in Hospice Architecture", an overview of historical background of the contemporary hospice and its basic principles of design. Another book by Ken Worpole in 2009, "Modern Hospice Design", elaborates the architectural design challenges for palliative care. A series of hospice design guidelines and reports have published in Australia, UK and USA. In 2000, the "Hospice Unit Generic Brief" published in Australia. In 2005, the "Design Guidelines for Specialist Palliative Care Settings" has published by the Department of Health and Children of Irish government. Another guideline published in UK, "A Place to Die with Dignity: Creating a Supportive Environment" (NHS Estates 2005). In USA, the Hospice Education Institute published "Hospice Design Manual for In-Patient Facilities" (2006), written by Timothy Moorhouse. In 2010, Hospice Friendly Hospitals Programme published, "Quality Standards for End-of-Life Care in Hospitals". The King's Fund's Enhancing the Healing Environment (EHE) program published "Improving Environments for Care at End of Life" on lessons from eight pilot sites (Waller et al. 2008). Another report published on summary of evaluation findings by the King's Fund EHE (Aurthur et al. 2010). Among the ten articles, two are literature reviews (Brereton et al. 2011; and Rigby et al. 2010). Anderson (2007) studied patients' room design in palliative care unit. Two studies focused on environmental factors of end-of-life care at intensive care units (Fridh et al. 2007; Fridh et al. 2009). Silver (2004) focused on healing environments in end-of-life care. Tan et al. (2005) researched hospice environment on patient spiritual expression. Pease & Finlay (2002) focused on preference of single vs shared accommodation. Rowlands and Noble (2008) studied environmental impact and ward design. Kayser-Jones et al. (2003) identified physical environment is one of the three factors that influence end-of-life care in nursing homes. The dissertation by Swenson (2009) examined the designated hospice rooms in nursing home facilities and dissertation by Sargent (2012) explored design through relationship-centered end-of-life care.

A significant amount of studies focused on quality of care with different goals: quality of life in palliative care units (Cohen et al. 2001), quality of life for cancer patients (Cohen & Leis 2002), non-pharmacological caregiving activities (Lindqvist et al. 2012), quality of spiritual care (Puchalski et al. 2009), views on dignity (Franklin et al. 2006), influencing forces of care (Wilson & Daley 1998). Kayser-Jones et al. (2005) suggested a model hospice unit with three factors; care, community, and compassion. Seven studies focused on patients' perception and dying experience: Chinese patients' dying experience in nursing home (Chan & Kayser-Jones 2005), experience of living-dying of black and white older adults (Engle et al. 1998), ways of relating to death (Temestedt & Franklin 2006), minority and non-minority perspectives on what is a "good death" (Tong et al. 2003), physical and psychosocial suffering in the dying process (Schroepfer 2007), and cancer patients' experience towards death (Larkin et al. 2007; and Ryan 2005).

Family perception on hospice care has examined by ten studies with different objectives: identification of factors that influence quality of end-of-life care (Heyland et al. 2006; Russell et al. 2008; Stajduhar et al. 2011), end-of-life care in hospital (Hawker et al. 2006; Spichiger 2008), and end-of-life care in nursing home (Kaarbo 2010; Munn & Zimmerman 2006; Vohra et al. 2004; Vohra et al. 2006; Wilson & Daley 1999). Staffs' perspective on hospice care has studied by Brazil et al. (2004) and Evans et al. (2006). Dissertation by Nakashima (2002) investigated the psychosocial and spiritual well-being of older adults at end-of-life.

3.0 ANALYSIS & FINDINGS

This stage considered extraction of data from these 48 literatures onto a standard template (matrix) for comparison and analysis. Data analysis considered coding and thematic development. For analysis, this study used preset themes (e.g. safety, autonomy, functionality) during extracting data and also opens to identify the new themes. The study has identified eleven Therapeutic Goals (TGs) for hospice environment:

1. *Provide continuity of self*
2. *Provision of access to nature*
3. *Provision of privacy*
4. *Facilitate social interaction*
5. *Maximize safety & security*
6. *Provision of autonomy*
7. *Regulate stimulation*
8. *Provision of spiritual care*
9. *Maximize support for staff*
10. *Provide family accommodation*
11. *Provide support after death*

As this list illustrates, many dimensions are consistent with the aging and environment literature (e.g. safety & security, stimulation), but others emerge as particularly salient in the hospice care environment, such as spiritual care or support after death. Even where the environmental dimensions are consistent, the meanings of those dimensions are considered somewhat differently due to the very specific needs surrounding the dying experience. The first eight dimensions have direct influence on patients' experience of hospice care environment, and the last three goals have indirect influence on patients' experience (e.g. support for staff). Due to the space limitations, this paper limits its discussion to the first eight therapeutic goals which are directly related to the wellbeing of the patients and their experience. Table-1 shows the relationship of each citation to specific environmental dimensions which emerged as common through the thematic analysis of the full set of literature.

Table 1: Matrix of Literatures and Therapeutic Goals

Therapeutic Goals / Literature (Author, Year)	*Continuity*	*Nature*	*Privacy*	*Social*	*Safety*	*Autonomy*	*Stimulation*	*Spiritual*
Anderson 2008	●	●	●	●		●	●	
Arthur et al. 2010								●
Brazil et al. 2004			●	●	●	●	●	●
Brereton et al. 2011	●	●	●	●	●	●		
Chan & Kayser-Jones 2005								●
Cohen et al. 2001	●		●	●		●	●	●
Cohen & Leis 2002		●	●	●		●		●
Department of Health and Children 2005	●	●	●	●	●	●	●	●
Engle et al. 1998				●				●
Evans et al. 2006	●	●		●	●			
Franklin et al. 2006		●		●			●	
Fridh et al. 2007			●	●				
Fridh et al. 2009			●	●				
Hawker et al. 2006	●			●		●		
Heyland et al. 2006				●				
Hospice Friendly Hospitals 2010				●				●
Hospice Unit Generic Brief 2000	●	●	●	●	●	●	●	●
Kaarbo 2010				●	●			
Kayser-Jones et al. 2003						●		●
Kayser-Jones et al. 2005	●			●				
Larkin 2007	●		●	●	●			
Lindqvist et al. 2012	●	●		●	●	●	●	●
Moorhouse 2006	●	●	●	●	●	●	●	●
Munn & Zimmerman 2006	●			●				
Nakashima 2002	●	●		●				●
NHS Estates 2005	●	●	●	●		●	●	●
Pease & Finlay 2002			●	●				
Puchalski et al. 2009								●
Rigbi et al. 2009	●		●	●				●
Rowlands & Noble 2008		●	●	●				
Russell et al. 2008							●	
Ryan 2005		●		●				●
Sargent, 2012	●	●	●	●	●	●	●	●
Schroepfer 2007				●				
Silver 2004	●			●		●	●	●
Spichiger 2008	●			●		●		
Stajduhar et al. 2011			●		●	●	●	
Swenson 2009	●	●	●	●		●		
Tan et al. 2005				●				●
Ternestedt & Franklin 2006	●			●				
Tong et al. 2003	●			●				●
Verderber & Refuerzo 2006	●	●	●	●	●	●	●	●
Vohra et al. 2004			●	●				
Vohra et al. 2006			●	●		●		●
Waller et al. 2008	●	●	●	●		●	●	●
Warpole 2009	●	●	●	●		●	●	●
Wilson & Daley 1999			●					●
Wilson & Daley 1998			●					●

The next section will discuss each therapeutic goal, the definition of each goal, and highlight the evidence suggestive of the appropriateness of this goal.

Therapeutic Goal – 1: *Provide Continuity of Self*
Definition: Environmental characteristics that help preserve or support patients' past activities, preferences and awareness.

> Patients experience complex emotion, a sense of instability, and impermanence during the transition towards death (Department of Health and Children 2005; Larkin et al. 2007). Lack of familiarity and disorientation with the surrounding environment influences patients' emotions, as well as their quality of life (Nakashima 2002; Cohen et al. 2001; Brereton et al. 2011; Rigbi et al. 2009; Worpole 2009; Hawker et al. 2006). Hospice environment should offer a place where the shifting boundaries of home could be re-created to achieve a meaningful surrounding and to ease transition from home to institution (Larkin et al. 2007). The creation of a domestic or home-like environment is the most desirable characteristic for dying patients to achieve their continuity of self (Swenson 2009; Tong et al. 2003; Rijbi et al. 2009; Brereton et al. 2011; Larkin et al. 2007; Moorhouse 2006; Anderson 2008; Verderber & Refuerzo 2006; Evans et al. 2006; Kayser-Jones et al. 2005; Ternestedt & Franklin 2006; Munn & Zimmerman 2006; Cohen et al. 2001; Silver 2004).

Therapeutic Goal – 2: *Provision of Access to Nature*
Definition: Environmental characteristics that provide opportunities for visual and physical access to nature.

> Having a connection with the outdoor nature is a significant criterion for hospice care; nature is conjectured to improve patients' mind, spirit, comfort and satisfaction (Rowlands & Noble 2008; Evans et al. 2006; Nakashima 2002; Cohen & Leis 2002; Brereton et al. 2011; Warpole 2009; Franklin et al. 2006). Dying patients typically spend increasing amounts of time indoors and become increasingly confined in a limited space (Nakashima 2002). If conditions allow, patients should access an outdoor garden or veranda, but certainly should possess a view of the natural landscape through a window; a view to nature can enhance patients' positive feelings, reduce fear and anxiety, can help to reduce pain, and maintain a calm state of mind (Swenson 2009; Moorhouse 2006; Verderber & Refuerzo 2006; Nakashima 2002; Rowlands & Noble 2008; Cohen & Leis 2002; Ryan 2005; Diette et al. 2003). Natural light is important in feeling of well-being (Anderson 2008) and fresh air ameliorates the indoor air toxicity and lessens the controlled feeling of a 24/7 air-conditioned environment (Verderber & Refuerzo 2006). Hospice environment should provide the opportunities for visual and physical access to nature.

Therapeutic Goal – 3: *Provision of Privacy*
Definition: Environmental characteristics that facilitate patients' choices in various levels of privacy through regulation of visual and auditory stimuli.

> For dying persons, privacy is particularly salient to the dignity, independence, quality of life, and the emotional well-being (Hospice unit generic brief 2000; Moorhous 2006; Brereton et al. 2011; Rijbi et al. 2009; Stajduhar et al. 2011; Sargent 2012; Department of Health and Children 2005; Brereton et al. 2011; Cohen et al. 2001; Swenson 2009; Cohen & Leis 2002; NHS Estates 2005; Brazil et al. 2004; Vohra et al. 2004). Lack of privacy due to the presence of a roommate and excessive noise often creates concerns (Vohra et al. 2006; Cohen et al. 2001).

Therapeutic Goal – 4: *Facilitate Social Interaction*
Definition: Environmental characteristics that facilitate and enable meaningful interaction between patients with staff, their family and other patients.

> Presence of others, especially the physical and emotional proximity to loved ones during the dying experience is one of the key themes of a good death; it improves patients' social life and lessens the feeling of loneliness (Tong et al. 2003; Brereton et al. 2011; Evans et al. 2006; Hawker et al. 2006; Fridh et al. 2007; Brazil et al. 2004; Cohen & Leis 2002; Rijbi et al. 2010; Moorhouse 2006). To facilitate patients' social life, accommodation of family and visitors has emphasized (Munn & Zimmerman 2006; Ryan 2005; Spichiger 2008; Tan et al. 2005; Vohra et al. 2004; Ternestedt & Franklin 2006; Silver 2004; Vohra et al 2006; Hawker et al. 2006; Swenson 2009; Moorhouse 2006; Hospice Friendly Hospice 2010; Nakashima 2002; Franklin et al. 2006). Some studies found patients get benefit interacting with other patients, it offers them self-reflection, mutual empathy, support, and companionship of this lonely journey (Munn & Zimmerman 2006; Cohen et al. 2001; Rowlands & Noble 2008; Rijbi et al. 2010; Anderson 2008; Larkin et al. 2007; Pease & Finlay 2002; Engle et al. 1998).

Therapeutic Goal – 5: *Maximize Safety & Security*
Definition: Environmental characteristics that maximize patient safety and security of self.

> Safety and security is one of the prime issues of any healthcare facility, and there is a significant amount of research that has suggested in-depth design considerations related with safety and security of hospice care environment for patients: accessibility (by disable persons), fire safety codes, protection from theft & vandalism, protection from fall or slip, infection control, etc. (Department of Health and Children 2005; Moorhouse 2006; Verderber & Refuerzo 2006; Stajduhar et al. 2011; Brereton et al. 2011; Evans et al. 2006; Lindqvist et al. 2012; Larkin et al. 2007; Kaarbo 2010; Hospice unit generic brief 2000).

Therapeutic Goal – 6: *Provision of Autonomy*
Definition: Environmental characteristics that enable patients to exercise choice and personal preference about their environment and everyday life.

> Humans need a sense of control and losing this can lead to depression and other serious problems; having personal control over the ambient environment (lighting, noise, temperature), communication (phone, nurse calling system) and daily routine (food, personal hygiene, sleep, recreation, music, or family visit), is one of the key considerations before death (Cohen & Leis 2002; Swenson 2009; Silver 2004; Lindqvist et al. 2012; Department of Health & Children 2005; NHS Estates 2005; Tan et al. 2005; Anderson 2008). It is significant to understand the patient's wishes and allow exploration of choices (Lindqvist et al. 2012).

Therapeutic Goal – 7: *Regulate Stimulation and Support Therapies*
Definition: Environmental characteristics that contribute to an appropriate quantity and quality of sensory experience, and support palliative therapies.

> Sensory stimulation offers therapeutic treatment for pain, depression and many other symptoms, which are basic criteria of palliative care (Department of Health & Children 2005). Different types of sensory therapies (music, aroma, art, massage, spa/hydro, multi-sensory, etc.) are increasingly used in hospice or palliative care to improve patient's quality of life (Department of Health & Children 2005; Russell et al. 2008; Brazil et al. 2004). Environmental factors can influence patients' sensory experience; a meaningful view improves stress and reduces pain, color can affect mood, exposure to daylight reduces depression and eases pain, artwork (e.g. paintings, sculptures, water features) has multiple benefit (e.g. art representing nature evokes positive response), and water features have a relaxing effect (Verderber & Refuerzo 2006; Moorhouse 2006; Department of Health & Children 2005).

Therapeutic Goal – 8: *Provision of Spiritual Care*
Definition: Environmental characteristics that facilitate opportunities for patients' spiritual care; religious, philosophical, existential, and personal beliefs, values, practices, and preferences.

> Spiritual care is a fundamental component of hospice care to support patients' personal striving for health, wholeness, comfort, and meaning of life (Hospice Unit Generic Brief 2000; Brazil 2004; Puchalski et al. 2009; Department of Health & Children 2005; Tong et al. 2003; Rigbi et al. 2009; Vohra et al. 2006; Cohen & Leis 2002; Cohen et al. 2001; Silver 2004; Nakashima 2002; Hospice Friendly Hospitals 2010; Ryan 2005; Engle et al.1998). Each person's definition of spirituality is individualized and may or may not include a religious preference, so spiritual care should be defined broadly, such as, meaning-oriented therapy, meditation, sacred/spiritual readings or rituals, yoga, art therapy, etc. (Puchalski et al. 2009). Hospice environment should facilitate religious or spiritual rituals or practices as desired by patient and family, especially at the time of death (Kayser-Jones et al. 2005).

CONCLUSION

This research engaged an exhaustive and systematic literature review in order to distill the salient environmental dimensions and subsequently, the therapeutic goals the hospice literature suggests are essential to promote in the hospice environments. These eight therapeutic goals can provide a sense of direction for planning and applying design skills more effectively and in greater concordance with the best practices of hospice care. We believe such lateral theoretical connections enable improvement in management procedures and the articulation of user requirements.

The study has numerous limitations and should be considered an initial effort at establishing this common language for connecting organizational and physical design decisions in a sympathetic and mutually reinforcing fashion. First we limited discussion to the first eight therapeutic goals solely due to the limitations

of space, and therein make no value judgment regarding the importance of the last three therapeutic goals that were not discussed. Second, this study has also identified the design criteria for each therapeutic goal which are also not presented due to space limitations. Third, the literature review was conducted in such a way that it did not consider the conference proceedings relevant to hospice or palliative care which may contain very meaningful insight to this question. Fourth, the interpretation was conducted and limited to two researchers which did engage in peer examination and a code-recode procedure, the study could be enhance through further expert validation. This could be done, for instance, through utilization of the Delphi Method to obtain opinions about these therapeutic goals from a multidisciplinary experts' panel.

We believe that these eight therapeutic goals provide a useful point of departure in which to engage in effective, systemic place making. While much research focuses on the nexus amongst staff, families and patients, the physical environment is a palpable, albeit silent partner in any care milieu. Further work in this trajectory ought to include further in-depth literature review in regard to each specific therapeutic goal to identify more in-depth criteria by referencing relevant information developed in related care domains (e.g. cancer care). The development of an environmental assessment instrument organized according to these therapeutic goals would be informative to both assess existing environments but also to inform design decision-making. As our understanding of hospice care advances, we believe that these therapeutic goals can inform the creation of better hospice environments and thereby more dignified dying experiences for patients, their families and caregivers.

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